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## **Abstract**

**Aim:** Looking after someone in the early stages of psychosis can have a negative impact on caregivers but there is little clarity about which interventions, if any, caregivers should be offered. This study investigated sleep disturbances in early psychosis caregivers and the relationship between their sleep quality and distress.

**Method:** 79 caregivers of people with a recent first-episode of psychosis completed self-report measures including the Pittsburgh Sleep Quality Index (PSQI), the SF-36-Health Survey (SF-36) and the Experiences of Caregiving Inventory (ECI).

**Results:** All caregivers were living with their relative with psychosis and had been providing support since the onset of illness (mean duration = 92.5 weeks, s.d. = 84.0). Sixty-percent (47/79) obtained a global PSQI score that exceeded the established cut-off for clinically significant sleep problems ( $>5$ ). Low 'sleep duration' and 'sleep disturbances' contributed most to elevated PSQI scores, with 17.7% of participants reporting regular waking at night due to 'stress' or 'worries'. When predicting psychological distress (SF36) from negative appraisals of caregiving (ECI) and poor sleep (PSQI), a significant unadjusted regression model was obtained,  $F(2,73) = 29.440$ ,  $p = .000$ ,  $R^2$  of .447. An estimation of the indirect effect of negative thoughts about caregiving on mental distress through poor sleep was also significant  $ab = -.05$ , 95% CI  $[-.09, -.02]$ ,  $P_M = .39$ ).

**Conclusion:** Caregivers of people with psychosis may have significant problems with sleep, which relates to distress and negative appraisals about caregiving. Services need to ask caregivers directly about such issues, and consider offering brief interventions to improve sleep quality.

**Keywords:** Caregivers, Psychosis, Early Episode, Sleep, Distress, Brief Interventions

## **Background**

Stress responses in caregivers of people in the early stages of psychotic illness can include symptoms of anxiety, depression and trauma (Jansen, Gleeson, & Cotton, 2015, Barton & Jackson, 2008; Kingston, Onwumere, Keen, Ruffell, & Kuipers, 2016). Caregiver distress has additionally been associated with high Expressed Emotion in early caregiving relationships, or critical or overinvolved interactions with patients (Sadath, Muralidhar, Varambally, Gangadhar, & Jose, 2017; Tomlinson, Onwumere, & Kuipers, 2014). These potential health impacts of caregiving have led to the development of a range of interventions that aim to improve outcomes for caregivers of people with psychosis and in turn those to whom they provide care (Yesufu-Udechuku et al., 2015). Nevertheless, it remains unclear whether and when psychological interventions for caregivers should be offered to families and of exactly what these should consist when provided by statutory services with limited resources (Onwumere, Grice, & Kuipers, 2016).

Notably absent from the literature on psychological interventions for caregivers in psychosis are routine assessments of sleep difficulties. This is despite consistent reports of a strong correlation between disrupted or restricted sleep and psychiatric morbidity in other caregiving populations (McCurry, Song, & Martin, 2015). Studies suggest that patient-reported sleep disturbances are prevalent in early psychosis and may be associated with increased symptom severity, rates of help-seeking and suicidality (Davies, Haddock, Yung, Mulligan, & Kyle, 2017). There is also evidence to suggest that longer-term psychosis caregivers may be more likely to report sleep difficulties than both non-caregivers and other caregiving populations e.g. in Alzheimer's disease, stroke or cancer (Gupta, Isherwood, Jones, & Van Impe, 2015). However, the quality of sleep reported by caregivers in early psychosis has yet to be examined, together with its potential relevance to other caregiver outcomes.

The current study aimed to assess the frequency and quality of sleep disturbances in early stage psychosis caregivers. We hypothesised that poor sleep would predict psychological distress in caregivers and we tested for an indirect relationship between negative appraisals or interpretations of caregiving and distress through poor sleep, drawing on the evidence from other caregiving populations (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). Evidence suggests that the way in which caregivers appraise or interpret their experiences is a strong predictor of their wellbeing (Raune, Kuipers, & Bebbington, 2004).

## **Method**

Ethical approval for the study was granted by the Berkshire Research Ethics Committee, UK, REF: 10/H0505/79. Participants were recruited via Early Intervention (EI) clinical services across London. Caregivers were identified by both service users and themselves as fulfilling a main caregiving role. To be included in the study they had to have maintained regular contact with service users, of at least 10 hours per week, with a minimum of one face-to-face interaction per week, over a period of at least three months. Caregivers completed questionnaires for the study as part of a face-to-face interview conducted at home or in a clinical setting of their choosing.

## **Measures**

Pittsburgh Sleep Quality Index, (PSQI), (Buysse, Reynolds III, Monk, Berman, & Kupfer, 1989)

The PSQI is a screening tool for sleep dysfunction in non-clinical and clinical samples and comparisons can be made across populations in terms of global PSQI scores (Mollaveya et al., 2016). Several studies have reported sound reliability and validity for the 19-item self-report measure (Mollaveya et al., 2016) and the scale has been used effectively in studies of caregivers (e.g. Lerdal et al., 2016). An overall score is generated from 7 subcomponents that

assess: Sleep Duration, Sleep Latency, Habitual Sleep Efficiency, Sleep Disturbances, Use of Sleep Medication, Daytime Dysfunction and Subjective Sleep Quality. Total scores range from 0-21, with higher scores indicating poorer sleep quality over the past month. A sum score of > 5 has been shown to differentiate ‘poor’ sleepers (e.g. individuals with sleep disorders or psychiatric conditions such as Major Depressive Disorder) from control groups (Buysse et al., 1989; Mollaveva et al., 2016).

Experience of Caregiving Inventory, (ECI), (Szmukler et al., 1996)

The ECI is a 66-item questionnaire that was designed to measure caregiving experiences in severe mental illness, with a particular focus on subjective appraisals of the caregiving role, care-recipient behaviours and symptoms (Szmukler et al., 1996). The instrument was developed and validated within psychosis groups (Harvey et al., 2008). It is a strong predictor of caregiver distress in psychosis (Jansen et al., 2015). The questionnaire consists of eight negative subscales (difficult behaviours, negative symptoms, stigma, problems with services, effects on the family, the need to provide back-up, dependency, loss) and two positive subscales (rewarding personal experiences, good elements of the relationship). Items are scored on a 5-point Likert scale reflecting the ‘time spent thinking’ on these in the past month. The ranges for overall summed subscales are ECI-negative = 0-208 and ECI-positive = 0-56.

RAND 36-item Health Survey 1.0, (SF36), (Ware & Sherbourne, 1992)

The SF-36 is an internationally validated self-report measure of generic physical and mental health outcomes (Stewart & Ware, 1992; Ware & Sherbourne, 1992). It was selected as a dependent-variable measure of caregiver distress for this cross-sectional study because it captures the functional or behavioural impact of perceived mental ill-health (i.e. the extent to which daily activities have been limited by emotional problems). Furthermore, it has

demonstrated strong reliability, validity and sensitivity in discriminating changes across general population and patient groups, including caregivers (Gutiérrez-Maldonado, Caqueo-Úrizar, & Kavanagh, 2005; McHorney, Ware, Lu, & Sherbourne, 1994). Four out of eight available health domains were used to compute the Mental Component Summary Score (SF36-MCS) including questions on vitality, role limitations due to personal or emotional problems, social functioning and general mental health. Norm-based scoring (population mean = 50, s.d = 10) was employed using US population norms and following the computational rules for combining items outlined in the components manual (Ware, Kosinski & Gandek, 2000). Evidence supports the applicability of US algorithms to UK populations (Jenkinson, 1999; Ware et al., 1998) and this approach enabled comparison with other studies of psychosis caregivers (e.g. Gupta et al., 2015).

### **Statistical analysis**

Descriptive statistics were calculated to summarise socio-demographics and the quality of sleep reported by caregivers. The distribution of all variables was examined graphically. Linear relationships between negative caregiving experiences (ECI-neg), poor sleep (PSQI) and mental distress (SF-36 MCS) were assessed using multiple regression. To explore the mechanisms by which negative thoughts about caregiving might influence mental distress, a mediation model estimating the potential indirect effect through poor sleep was tested using a non-parametric bootstrapping procedure, with biased corrected confidence intervals obtained with 5000 bootstrap resamples (Hayes & Rockwood, 2016). Unadjusted statistics were calculated, together with those adjusted for caregiver age, gender and time spent caregiving. Percentage mediation was calculated as an indication of effect size. All analyses were conducted in SPSS 22. The PROCESS Macro for SPSS (version 2.16.3; Hayes, 2013) was used for regression modelling.

## Results

### *Caregiver characteristics*

A total of 79 caregivers consented to the study and completed the measures. The majority were mothers looking after adult sons. Full sociodemographic details are given in Table 1. All participants had been providing caregiving support since the onset of their relative's illness. The mean duration of caregiving was estimated based on illness time in weeks from first admission or registration date with EI services (mean = 92.5,  $\pm$  84.0, min = 9, max = 313). The ethnic diversity of the sample principally reflected the communities served by EI teams in South London.

### INSERT TABLE 1

### *Sleep complaints*

Sixty-percent of caregivers (47/79) exceeded a PSQI cut-off score of 5. Analysis of the mean scores on the PSQI subcomponent scales (Figure 1) indicated that low amounts of sleep (duration) and sleep disturbances made the greatest contribution to higher global PSQI scores, followed by difficulties getting to sleep (latency). Some 17.7% of caregivers (14/79) reported regular sleep disturbances due to 'worries' and 'stress'. This was a majority of those who chose to respond to an open-ended question about additional reasons for lack of sleep (58%, 14/24). Although caregivers were aware of poor sleep (overall), medication use remained low.

### INSERT FIGURE 1

***Negative thoughts about caregiving, poor sleep and perceived mental distress***

A multiple linear regression model was calculated to predict mental distress (SF36-MCS, mean = 37.8, s.d = 9.4, range = 9-53) based on negative thoughts about caregiving (ECI-neg, mean = 77, s.d = 34.9, range = 8-167) and poor sleep (PSQI, mean = 7.3, s.d = 4.6, range = 0 - 21). Three cases with missing data were excluded from the analysis (n=76). A significant unadjusted regression equation was found using bootstrapping procedures,  $F(2,73) = 29.440$ ,  $p = .000$ ,  $R^2$  of .447. SF-36 mental wellbeing scores decreased by roughly a unit for every single unit increase on the PSQI and decreased by a unit for every 13 points gained on the negative subscale of the ECI. A statistically significant indirect effect was also found of negative thinking about caregiving on functionally-impairing mental distress through poor sleep. As Figure 2 illustrates the standardized regression co-efficient for this indirect effect was  $(.05 \times -1.02) = -.05$ , 95% CI [-.09, -.02]. The analysis suggested that poor sleep might account for greater than a third ( $P_M = .39$ ) of the total effect of negative appraisals of caregiving on mental distress. Negligible differences were obtained when the model was adjusted for caregiver age, gender and time spent caregiving. Please see Appendix 1 for adjusted statistics.

**INSERT FIGURE 2****Discussion**

The study set out to examine potential sleep disturbances in caregivers supporting someone in the early stages of psychosis. Additionally, we aimed to assess whether hypothesised poor sleep quality might operate as a mechanism by which negative thoughts about caregiving might influence mental distress in caregivers. The results were revealing as to the potential extent of sleep difficulties in caregivers of individuals with early psychosis. Nearly two-thirds of included caregivers reported sleep disturbances at levels comparable to previous samples



receiving treatment for clinical sleep disorders and in the context of psychiatric conditions (Mollaveva et al., 2016). A mean global PSQI score of 7, for example, obtained in the present study equates to ‘severe’ difficulties reported across two sleep dimensions, or ‘moderate’ difficulties across three. Caution must be reserved in making comparisons with other studies that have employed different criteria for insomnia (Roth, 2007). Nonetheless, around 40% of women of the same age in the general population might be expected to report at least one symptom of insomnia, with only 10-15% reporting more moderate sleep problems (Stewart et al., 2006). The results obtained in this study were consistent therefore with other studies that have found the rate of severe sleep problems in caregivers of individuals with complex needs to be notably higher than general population estimates e.g. in advanced cancer caregivers (Maltby, Sanderson, Lobb, & Phillips, 2017). Additionally, a greater frequency and chronicity of sleep problems was found in this early episode sample of caregivers than has previously been found in caregivers of individuals with schizophrenia that did not specify time spent caregiving (Gupta et al., 2015).

We cannot assume that the sleep disturbances reported here arose solely as a result of caregiving experiences. However, a significant correlation was observed between negative appraisals of caregiving and sleep in the absence of a strong influence of other factors (i.e. . caregiver age, gender or time spent caregiving). The lack of significant correlations observed between the co-variables and the level of mental distress in this sample may be due to limited variability in the predictor variables. The majority of the sample were females of a similar age, caregiving in the early stages of illness.

The results of the regression analyses raise questions as to the clinical importance of the relationships between negative thoughts about caregiving, poor sleep and mental distress. The use of norm-based scoring for the SF-36 allowed for a comparison with a general population norm of 50 and a standard deviation of 10. MCS scores typically range between 20 and 60,

and minimal clinically important changes have been estimated at approximately 2-3 points (Maruish, 2011). In the regression model calculated, increased scores between 10 and 20 on the ECI negative subscale (range = 0-208) were predictive of one unit changes on the PSQI (range = 0-21, cut-off of 5) and MCS (range = 9-53), either by direct or indirect estimations. The co-efficients in the regression equation may appear small, but given the potential clinical relevance of 2-3 unit shifts on the PSQI and SF-36 MCS, and the comparatively larger scale of the ECI, the statistical model would seem to be consistent with an inference of clinically relevant associations.

The findings are also supported by an examination of the mediating role of sleep on mental health in community caregivers (Phillips et al., 2009). This previous study highlighted the importance of sleep for mental distress, and underlined the need for sleep interventions for these caregivers. To our knowledge, a sleep intervention has yet to be systematically considered as part of therapeutic protocols for caregivers of individuals with psychosis. Yet their application and efficacy has been explored in other caregiving populations (McCurry et al., 2015). For example, brief cognitive, behavioural interventions targeting poor sleep have been shown to be acceptable and feasible to caregivers of people with dementia (Simpson & Carter, 2010). Evidence suggests efficacy in reducing insomnia and symptoms of depression, with lasting effects up to 4 months (Carter, 2006).

Finally, the finding that sleep may be influential in explaining the relationship between negative appraisals of caregiving and distress has implications for psychological interventions for families. Established caregiver interventions in psychosis comprise a range of different therapeutic elements including, psychoeducation, stress management, facilitating adaptive coping and working with unhelpful beliefs (Yesufu-Udechuku et al., 2015). There are many studies supporting the general efficacy of caregiver interventions, including at early episode (Claxton, Onwumere, & Fornells-Ambrojo, 2017). However, evidence is still emerging in

support of the relative importance of different elements in improving specific caregiver outcomes (Lobban et al., 2013). Improving sleep may need to be added to caregiver interventions that, for example, attempt to work with cognitions or negative appraisals of caregiving. Previous research, has found a dose-response effect of sleep-deprivation on generative cognitive tasks, suggesting that re-appraisals of emotions and emotional circumstances might be disrupted when sleep quality is poor (Van Dongen, Maislin, Mullington, & Dinges, 2003). Indeed, there is a growing evidence base to suggest an important role for sleep in emotion regulation and expression (Palmer & Alfano, 2017). Brief sleep interventions may offer an avenue by which to help caregivers to improve their mood and overall wellbeing.

### **Limitations**

Given the cross-sectional nature of the data, causal inferences can only be indicated. The mediation model tested necessarily oversimplifies the complex interactive relationships between appraisals of caregiving, sleep and distress. For example, we were unable to account for whether sleep was a proxy for mood changes or to control for prior sleep problems unrelated to caregiving. Nonetheless, we tried to embed our predictions within current cognitive theory and to select appropriately robust measures to support the proposed models (Hayes and Rockwood, 2016). Additionally, we were unable to corroborate caregiver reports of sleep problems (Lauderdale et al., 2008).

### **Conclusion**

Early psychosis caregivers need assessment of sleep problems and the offer of brief interventions to improve outcomes.

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**Tables****Table 1: Sociodemographic characteristics of early psychosis caregivers and patients**

	Proportion in %, (n)
Total number of caregivers	(79)
Gender: Female	86, (68)
Age (mean years)	51.8 ± 8.8
Relationship to patient: Parent	90, (71)
Living with SU	80, (63)
Face-to-face contact (hours)	mean = 17.7 ± 14.0
Ethnicity:	
White British	43, (34)
Black British	16, (13)
Black Caribbean	20, (16)
Black African	14, (11)
Other	7, (5)
Employment status:	
FT paid	27, (21)
PT paid	21, (17)
Self-employed	14, (11)
Unemployed/sick leave/incapacity benefit	25, (20)
Retired/volunteering/studying	13, (10)
Marital status:	
Single	34, (27)
Married/civil or long term partner	60, (47)
Divorced/separated/widowed	6, (5)
Patients: Gender: Male	69, (54)
Age (years)	mean = 24.5 ± 4.6
Illness time (weeks since first admission)	mean = 92.5, ± 84.0, min = 9, max = 313
No. of inpatient admissions	mean = 1.0, min = 0, max = 4

*Figure Titles*

**Figure 1:** Mean scores on the PSQI subcomponent scales

**Figure 2:** Estimating the indirect effect of negative thoughts about caregiving on mental wellbeing through poor sleep, unadjusted regression model

*Appendices***Appendix 1: Estimating the indirect effect of negative thoughts about caregiving on mental wellbeing through poor sleep, adjusted regression statistics**

Taking into account caregiver age, gender and time spent caregiving, a significant adjusted regression equation was found,  $F(5,70) = 12.184$ ,  $p = .000$ ,  $R^2$  of .465. The standardized regression co-efficient for the indirect effect was  $(.05 \times -1.06) = -.05$ , 95% CI  $[-.10, -.02]$ . Correlations between co-variates and the dependent variable were non-significant.